Stefan Gijssels â?? Chairman, Patient Expert Center, Belgium

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29.05.2023

Tags:

Belgium, Patient Expert Center, Patients, Patient Association

The concepts of patient-centricity and patient-centred healthcare systems have been much discussed in recent years but, in the opinion of Stefan Gijssels, there is still a long road to travel to fully realise them. Gijssels â?? a 20-year pharma industry veteran whose personal experience of cancer led to him joining the patient advocacy field â?? calls for a more holistic and systemic approach to healthcare. He also foregrounds the importance of a greater understanding of the patient journey and more integration of data to improve systems, generate better health outcomes, and reduce costs.

Having had a 20-year career in the pharmaceutical industry, can you begin by sharing the story of what spurred you to join a patient association?

The main motivation to join the patient association field and the Patient Expert Center came after my own experience with cancer. Once I was declared cancer-free, I felt a strong desire to use my knowledge and experiences to benefit other patients and become a patient advocate. As a pharmaceutical specialist, I have always advocated for value-based healthcare, which is a key goal for the industry in terms of improving health outcomes and delivering better value. However, I was surprised to see that certain aspects of care were completely overlooked, regardless of the overall outcome. Despite receiving treatment at one of the top cancer hospitals in Europe with excellent survival statistics, I personally encountered several areas where things could have been significantly improved, such as diagnosis, patient information on nutrition, on physical exercise, on access to reimbursement and social services, and on the availability of supportive care. Patients are often left to navigate these challenges on their own, without a system in place to guide them through their journey and address their holistic needs, including relationships, employment, nutrition, and physical activity.

One of the key realizations I had was that the current healthcare system tends to overlook the bigger picture and lacks a holistic mindset. While the clinical aspects of treatment, like surgery and chemotherapy, may be well-managed, there is often a lack of attention to the broader patient journey. This leads to inefficiencies and wasted resources within the system. It became evident to me that a systematic approach is needed to capture and analyze patient data, with the aim of improving the overall patient experience and achieving better health outcomes at lower costs. Currently, much of the valuable information about what patients go through remains hidden and underutilized.

When people claim that the healthcare system is unsustainable and that medications, surgeries, and hospitals are too expensive, it is clear to me that they lack a comprehensive understanding of the system. There is a need to look beyond isolated elements and instead focus on the totality of the data to identify areas where efficiencies can be gained. By adopting a more integrated and process-driven approach, we can significantly improve the system, generate better health outcomes, and reduce costs. This is an area with immense potential for improvement.

How have you experienced your journey from the industry to chairman of the Patient Expert Center?

After leaving Johnson & Johnson, I reached out to Europa Colon, the European Association of colon cancer patients, and offered my volunteer assistance. Soon, they approached me about taking over the organization as the previous leader was retiring at the age of 73. I took on the task and relocated the organization from the UK to Brussels, establishing it as a new legal entity. We expanded our focus from colon cancer to encompass all digestive cancers, leading to the creation of Digestive Cancers Europe, an umbrella organization for digestive cancers in Europe: oesophageal cancer, pancreatic cancer, gastric cancer, liver cancer, colorectal cancer, and rare digestive cancers.

Our efforts extended beyond just the organization itself. We actively participated in the development of the European Beating Cancer plan alongside Stella Kyriakides. Additionally, I became a chair of the European Cancer Organizationâ??s patient advisory board and had the privilege of chairing the European Cancer Summit and European Cancer Forum multiple times. Presently, I am a member of the European Commission initiative on colorectal cancer, consistently engaging in policy circles to ensure that the patientâ??s voice is effectively represented.

Around two years ago, I collaborated with several patient organizations in Belgium to establish the Patient Expert Center. Unfortunately, the main coordinator of the initiative passed away, and I volunteered to take over as the Chairman of the organization. Since 2021, we have been actively involved in various areas, including rheumatic diseases, multiple sclerosis, childhood cancer, gynaecological cancers, diabetes, rare diseases, pulmonary hypertension, Crohnâ??s disease & colitis ulcerosa.

Can you elaborate on the key activities of the Patient Expert Center and the goals it aims to achieve?

The key activities of the Patient Expert Center revolve around training patients to become experts in their specific disease areas. This training spans six months and covers various aspects, including the healthcare system, patient rights, psychology, legal responsibilities, disease knowledge, treatment options, research updates, and living with the disease. We also provide courses on social services, nutrition, physical aspects, and mental well-being. At the end of each course, there is a test and individual interviews to assess their knowledge and skills. Those who pass receive a certificate, indicating their readiness to become active volunteers.

Once certified, these patient experts can engage in two main roles. They can consult with individual patients and their families, providing guidance and support throughout their disease and treatment journey. Alternatively, they can represent the organization in dialogues with hospitals, government services, insurance companies, and pharmaceutical companies. Our goal is to professionalize the patient perspective and ensure that the patient voice is heard by elevating the standard of patient organizations to a higher level.

To achieve this, we prioritize creating collaboration models between patient organizations and our professional partners, such as industry, hospitals, and government agencies. We identify core services where formal engagement with patient organizations would be beneficial. For example, with industry, we focus on areas like clinical trials, real-world evidence, market access, policy, and company culture. Similarly, with hospitals, we work on clinical pathway design, quality of care, health literacy, staff education, and governance representation. We develop a step-by-step approach, including flowcharts, for each interaction, which in turn leads to the establishment of contractual agreements designed to generate revenue to the patient organization for the services offered.

Our aim is to establish a Patient Expert Center quality label, indicating that processes in hospitals or companies have been designed in collaboration with us, with a focus on patient needs. This label can be used for competitive or differentiation purposes. Itâ??s important to note that our organization remains non-profit, as our primary goal is to work with the healthcare system to amplify the voices of patients and continue improving their experiences.

Why is it important for the patient perspective to be taken into account at this level of the healthcare system?

It is crucial to take the patient perspective into account at this level of the healthcare system because it provides valuable advantages. By considering both the medical/scientific perspective and the patientâ??s lived experience, we can make significant progress. Our intention is not to oppose science or technology but rather to emphasize the need for a holistic approach. Unfortunately, too often, the medical perspective alone dominates the discussion, overlooking important issues that are cost-effective but often ignored in healthcare. When I present examples to policymakers about the challenges patients face, they often dismiss them as anecdotal evidence. However, these experiences are not isolated incidents but often widespread occurrences affecting tens of thousands of patients every day. Theyâ??re anecdotal for the simple reason that nobody ever bothered to conduct systematic surveys on the issue. Systematically integrating the patient perspective in medical practice will optimise its effectiveness and efficiency.

How easy or difficult is it to recruit patients that have the readiness and professional capacity to invest their time and efforts into the mission of the Patient Expert Center?

Recruiting patients who are ready and have the professional capacity to invest their time and efforts into the mission of the Patient Expert Center is currently not a major challenge. In fact, we have more candidates than we can accommodate, which is a positive sign. We are able to select individuals who already possess a good level of education and motivation, which is critical for our work. Many of these individuals, particularly those with chronic diseases like rheumatic diseases, multiple sclerosis, and cancer, have faced challenges such as losing their jobs due to their conditions. Engaging in our mission gives them a renewed sense of societal value by contributing to the well-being of other patients.

However, this is not the sole driving force. I am continually amazed by the number of patients who, in addition to managing their own health, juggle responsibilities such as work and family, yet still choose to volunteer their time to help others. There are countless individuals who possess this desire to make a difference. Witnessing their dedication is energizing. However, it can also be frustrating when we encounter a lack of response from policymakers who fail to fulfill their responsibilities without facing any consequences. This is one of the significant challenges we face: ensuring that the patient perspective is not only valued but also acted upon by decision-makers.

How bureaucratic are the European and Belgian healthcare systems compared to those in countries like the US or the UK?

Belgian healthcare policy can certainly be described as bureaucratic, but it is also accessible. Itâ??s important to consider the political nature of the European system, which involves diverse political parties and member states with different organizational structures working together. To make progress, it is necessary to listen to the various stakeholders involved. In contrast, the United States tends to have a simpler dynamic between Republican and Democrat, while the UK has the Conservative and Labor parties. Europeâ??s complexity offers the advantage of slower but consistent progress without swinging back and forth between progressive and conservative ideologies. Although it may seem slow, this approach takes into account the expectations of multiple stakeholders. The task is not easy, and patient organizations operate with more limited resources, which may differ from countries like the US or the UK where these organizations are more powerful.

To what extent do Belgian policymakers take this patient perspective into account? How open are they to entering into conversations with patient organizations?

This perspective is often not adequately considered by policymakers, not just in Belgium but in many healthcare systems. There are umbrella organizations in both Flanders and Wallonia that represent patients at a transversal level, focusing on for instance patient rights and transportation. However, there is a need for disease-specific information and support for patients. For example, after a diagnosis, patients should have access to organizations that can provide holistic support beyond just clinical aspects. There are crucial issues that patients face, such as discussing death with family members in the case of childhood cancer or receiving nutritional advice after colorectal cancer surgery. These seemingly simple matters can have a significant impact on patientsâ?? well-being and recovery. Unfortunately, healthcare professionals often overlook or neglect these aspects, which can lead to complications and additional burdens on patients and their families. It is essential for policymakers to understand the importance of addressing these issues and to engage in meaningful conversations with patient organizations to ensure that the patient perspective is heard and incorporated into healthcare policies and practices.

Compared to a global context, Belgium is quite ahead of most countries as it invests approximately 11 percent of its GDP on health. As there is already a great deal of resources in the system, which is under strain nevertheless, do you expect this journey to implement a new holistic perspective to be challenging?

Implementing a new holistic perspective within the Belgian healthcare system may face challenges, but the existing resources and infrastructure provide a solid foundation for this journey. Belgium already invests a significant portion of its GDP in healthcare, and the system is well-equipped with advanced medical technology and highly educated healthcare professionals. In general, there is adequate funding in the system, although costs are increasing due to factors such as new drugs, surgical technology, and diagnostics.

However, one challenge lies in the design of the healthcare system itself, which is heavily influenced by the suppliers of services, such as hospitals, doctors, and insurers. The users of the system, namely the patients, are often left outside of the decision-making process. Suppliers naturally seek increased budgets each year, leading to a system that may not be sustainable in the long term. This creates a cycle of blame and frustration among different stakeholders.

The patient perspective is crucial in breaking this cycle and bringing rationality to healthcare policy. By considering the patientâ??s needs and experiences, it becomes possible to identify areas where improvements can be made. For example, colorectal cancer care in Belgium exhibits inefficiencies, with variations in hospital performance and outcomes. By addressing these issues and focusing on prevention and screening, significant cost savings can be achieved while improving patient outcomes.

Overall, while challenges may arise during the implementation of a holistic perspective, the existing resources and the inclusion of the patient perspective can help address these challenges and drive positive change in the Belgian healthcare system.

In your opinion, what do you see as a solution to this challenge of achieving holistic care?

The solution to achieving holistic care lies in the development of disease-specific plans or pathways. Each disease would have a designated pathway that outlines the necessary steps and processes for optimal care. Within these pathways, key statistics and data would be identified and measured, such as accurate diagnosis rates, stage of diagnosis, treatment timelines, mortality rates, survival rates, information needs of patients, and rates of complications or side effects.

By implementing this systematic approach, stakeholders including specialists, patient organizations, and policymakers can analyze the data and identify areas for improvement. They can compare results among different hospitals or healthcare providers and learn from those with the best outcomes. Best practices can be shared across the board to enhance care quality.

This approach requires collaboration and sharing of information among stakeholders. It is a basic process that can be implemented with the help of data analysis and the application of management principles. Despite the significant amount of funding invested in healthcare each year, there is often a lack of proactive efforts to identify and address areas for improvement. By adopting a structured approach and continuously monitoring and analyzing data, the healthcare system can make significant strides towards achieving holistic care and ensuring the sustainability of the system.

We can reasonably expect that it would take time for a government to carefully create these disease pathways. How do you expect to deal with innovation and novelty as there is a constant flow of new therapies, treatment strategies, and medical procedures?

The key is to integrate them into the holistic disease pathways and consider their impact on the overall system. Currently, innovation is often evaluated by comparing it to the existing standard of care, which can limit its acceptance due to cost considerations. However, a broader perspective is needed. For example, letâ??s consider the case of diagnostic tests. We have a cheap stool test for colorectal cancer, but there is also a more expensive liquid biopsy test that provides a more comprehensive analysis. If we compare these tests solely based on cost, the cheaper option appears more favourable. However, we should also consider the broader implications. The liquid biopsy test may be more expensive, but it could encourage more people to participate in screening due to its convenience. This increased participation can lead to early detection and improved health outcomes for the population as a whole, ultimately reducing the overall burden on the healthcare system.

The problem lies in the narrow perspective that often focuses only on immediate costs without considering the long-term benefits and cost-effectiveness. There is a need to look beyond individual costs and consider the cost of missed opportunities. By taking a comprehensive approach and considering the potential impact of innovations on the overall health economics of the population, we can make more informed decisions.

Unfortunately, the current system often lacks this broader view, resulting in inefficient use of resources. There is a need for a shift in mindset and a willingness to invest in prevention and early detection, even if it means upfront costs. By addressing diseases at a pre-symptom stage and implementing effective screening and prevention campaigns, we can achieve better outcomes and reduce the financial burden on the healthcare system.

It requires a change in the way we approach healthcare policy and decision-making, prioritizing long-term sustainability over short-term savings. By integrating innovation into the holistic disease pathways and considering the broader implications, we can ensure that new therapies, treatment strategies, and medical procedures are effectively incorporated into the system while maintaining a focus on overall health and cost-effectiveness.

As part of a new healthcare roadmap, the federal government is proposing an initiative called the Patient Council. What do you feel is the role of these kinds of government strategies versus patient organizations?

In this sense our goals are complementary and vital in achieving a patient-centered healthcare system. Government strategies, like the Patient Council, play a crucial role in setting the overall direction and framework for healthcare policies and initiatives. They have the power to shape the healthcare landscape, allocate resources, and implement systemic changes. The Patient Council, specifically, can serve as a platform for representing patient perspectives and ensuring that their voices are heard in policy discussions and decision-making processes. It can provide a formal mechanism for patients to engage with policymakers, share their experiences, and contribute to the development of patient-centered policies.

On the other hand, patient organizations have a unique and valuable role in advocating for the needs and interests of specific patient communities. They often have firsthand experience with the challenges faced by patients and can provide valuable insights into the realities of living with a particular disease or condition. Patient organizations have a direct connection to patients and can offer support, information, and resources tailored to their specific needs. They can also play a crucial role in raising awareness, providing education, and empowering patients to navigate the healthcare system effectively.

Ideally, government strategies and patient organizations should work together in a collaborative and coordinated manner. The government can provide support and funding to patient organizations to carry out their important work. This is the case in the Netherlands and Belgium ought to follow suit. In fact, from 2024 the Netherlands will double its subsidies to patient groups to reach EUR 46 million. I hope that the Belgium government can come to realize the opportunity to work together and give proper support for the value groups like the Patient Expert Center can bring.

Speaking about the industry, regulators often have a sceptical opinion about the interactions between patient groups and pharma companies in regard to creating demand for the approval of new medicines. What is your opinion on the relationship between the industry and patient organizations?

It is indeed an area for concern for the government, but they should increase their own financial support towards patient organizations if they have concerns about industry funding. The existence of patient organizations highlights the gaps and flaws in the healthcare system. If the healthcare system was truly effective in accompanying, supporting, and guiding patients, the need for patient organizations would be minimal. Patient organizations should ideally be a supplement to the healthcare system, providing additional support and resources, rather than filling the gaps left by the system. Itâ??s hypocritical for regulators to complain about industry funding patient organizations without increasing their own financial support. If they have concerns about industry influence, they should invest more in patient organizations themselves. The paid interactions we have with industry are all based on generating better understanding and outcomes, but without any conflicts of interest and in full compliance with all legislation.

I often engage in discussions with authorities, and Iâ??m not afraid to be more assertive in these conversations. It is important to challenge the notion that patient organizations are simply influenced by pharmaceutical companies. I challenge them to provide examples of pharma companies or patient organizations being steered by these companies to advocate for specific drugs. Itâ??s a fictional notion that they seem to repeat without evidence. While there may be instances where patient organizations advocate for drug reimbursement, it does not mean they are driven solely by the interests of pharmaceutical companies. For example, there have been debates surrounding demands for rare disease drugs, but patient organizations have been critical of drug prices and have called for more transparency in pricing.

I would argue patient organizations play a crucial role in representing patient perspectives, advocating for access to innovative treatments, and addressing pricing issues. Their insights on the value of drugs, including considerations of quality of life and patient preferences, are essential in shaping healthcare policies. Ultimately, the focus of these groups should be on improving the healthcare system to meet the needs of patients effectively. Their current existence should serve as a reminder that the system needs improvement and by addressing the underlying flaws we can create a healthcare environment where patients receive the care they need and patient organizations serve as a complement rather than a necessity.

Is there any final message you would like to deliver on behalf of the Patient Expert Center?

We need to shift the focus beyond just technology and infrastructure. While they are important, there is a wealth of untapped knowledge among patients and potential savings in areas that are currently ignored. We must shed light on all aspects of healthcare, not just what is new and innovative.

Patients have the right to be heard and supported. We advocate for every patient to be referred to a disease-specific patient organization after their diagnosis. These organizations can provide a welcoming and guiding environment for patients, helping them navigate their healthcare journey. Additionally, shared decision-making models should be implemented, allowing patients to express their preferences and have them incorporated into their treatment plans. Patients deserve to have a treatment plan that they have approved and that takes their individual needs and desires into account.

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